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# CLOSING THE GAP BETWEEN KNOWLEDGE AND PRACTICE IN THE U.S. LONG-TERM CARE SYSTEM

Larry Polivka\*

## INTRODUCTION

Long-term Care (LTC) has slowly emerged as a public policy issue over the last several years but has not yet achieved the level of visibility of issues like the growing number of medically uninsured or the fiscal sustainability of Medicare.<sup>1</sup> However, the aging of the baby boom generation is likely to make LTC an increasingly urgent concern for individuals and policy makers as the population age sixty-five and older doubles and the age eighty-five and older population triples over the next thirty years.<sup>2</sup> These demographic trends will create a growing demand for LTC services that will substantially increase the financial pressure on families and the public sector as they struggle to cover the cost of care.<sup>3</sup> The growth in LTC

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1. Joshua M. Wiener, *It's Not Your Grandmother's Long-Term Care Anymore!* 16 PUB. POL'Y & AGING REP. 28, 32 (2006); RICHARD W. JOHNSON ET AL., THE URBAN INST., MEETING LONG-TERM CARE NEEDS OF THE BABY BOOMERS: HOW CHANGING FAMILIES WILL AFFECT PAID HELPERS AND INSTITUTIONS 1 (2007), available at [http://www.urban.org/UploadedPDF/311451\\_Meeting\\_Care.pdf](http://www.urban.org/UploadedPDF/311451_Meeting_Care.pdf).

2. JOHNSON ET AL., *supra* note 1, at 1.

3. *Id.* at 2-3.

needs and costs are likely to push LTC to the top of the domestic policy agenda within the next ten years and increase public awareness of the gap between what we know and what we do in LTC.

Despite the fact that long term care is the third main pillar of retirement security along with health care and income support, it has not received the policy attention it deserves. There is no doubt that when the baby boom generation is age 80 or 85, long term care will be at the center of public policy debates, but those days are still quite far away (although not as far as they used to be). However, we are now at a time when the parents of the baby boom generation are now elderly; some of these parents are quite old and in need of long term care. It may be the combination of the baby boomers and their parents that put long term care on the national political agenda sooner rather than later.<sup>4</sup>

The major objectives of this article are to describe the knowledge and practice gap in LTC and the major barriers to closing the gap by providing more publicly-funded community-based LTC services; to identify a range of policy, funding, administrative, and litigation strategies that may be helpful in overcoming these barriers; and to provide an ethical framework designed to make LTC policy more than a technocratic concern for policy analysis and health economists. The article concludes with an argument for ending our dependence on Medicaid to publicly fund LTC services and for the development of a universal LTC program based, at least partially, on a social insurance funding strategy.

#### **CURRENT AND PROJECTED LONG-TERM CARE NEEDS, SERVICES, COSTS, AND PAYMENT SOURCES**

Approximately ten million Americans require some form of LTC assistance with the activities of daily living (ADLs), which include eating, bathing, dressing, toileting, and transferring.<sup>5</sup>

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4. Wiener, *supra* note 1, at 32.

5. KAISER COMM'N ON MEDICAID AND THE UNINSURED, MEDICAID AND LONG-

This population is set to increase by eight to ten million, with the growth of the age sixty-five and older population over the next three decades from thirty-six to seventy-eight million.<sup>6</sup> About 1.4 million people now receive LTC assistance in nursing homes; over a million receive paid assistance from either private or public sources; and the remaining six million plus are cared for by unpaid caregivers, mainly wives and daughters, in the informal system.<sup>7</sup> This informal help, which constitutes 70 to 80% of all LTC assistance, was worth over \$350 billion in 2006, which is about \$125 billion more than the dollar value of all paid (public and private) assistance and four times the amount of privately paid formal care (\$77 billion).<sup>8</sup> In November 2006, between thirty and thirty-eight million adult caregivers provided care to adults with LTC needs.<sup>9</sup> Caregivers averaged twenty-one hours of care per week and much higher hours for those providing care for someone with Alzheimer's disease.<sup>10</sup> Caregivers averaged about \$200 per month in out-of-pocket spending on LTC-related expenses.<sup>11</sup> LTC is clearly a very big issue from both a public policy and personal experience perspective and its saliency will increase enormously over the next several decades.<sup>12</sup>

The health and functional status of the age sixty-five and older population has improved significantly over the past thirty years and further improvement is expected in the future.<sup>13</sup> Nevertheless, the need for LTC assistance will increase very substantially with the doubling of the older population over the next thirty years unless there is a dramatic breakthrough in the

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TERM CARE SERVICES 1 (2007), *available at* <http://www.kff.org/medicaid/upload/7720.pdf>; JOHNSON ET AL., *supra* note 1, at 1.

6. JOHNSON ET AL., *supra* note 1, at 1.

7. *Id.* at 4, 22.

8. AARP PUB. POL'Y INST., VALUING THE INVALUABLE: A NEW LOOK AT THE ECONOMIC VALUE OF FAMILY CAREGIVING 3 (2007), *available at* [http://assets.aarp.org/rgcenter/il/ib82\\_caregiving.pdf](http://assets.aarp.org/rgcenter/il/ib82_caregiving.pdf).

9. *Id.* at 1.

10. *Id.*

11. *Id.* at 4.

12. *See* Wiener, *supra* note 1, at 32; JOHNSON ET AL., *supra* note 1, at 1.

13. JOHNSON ET AL., *supra* note 1, at iv.

prevention and treatment of Alzheimer's disease.<sup>14</sup> The capacity of the "unpaid" informal care system to provide the current level of assistance is likely to shrink due to relatively low birth rates since 1960 (smaller families) and an increase in the divorce rate over the last several decades.<sup>15</sup>

In 2040 there will be only nine adults age 25 to 64 to support each disabled older adult, down from 15 younger adults in 2000.<sup>16</sup> The number receiving paid home care is likely to more than double by 2040, growing from 2.2 million to over 5 million, and the number receiving care in nursing homes will double to about 2.7 million.<sup>17</sup> The average number of hours of paid help per disabled older person will grow by about a third, from 163 hours per month to 220 hours.<sup>18</sup>

This projected growth in the need for LTC services and the declining availability of paid and unpaid caregivers is likely to drive future LTC costs well above average annual increases of the past.<sup>19</sup> This growth in LTC spending will make the issue of how these resources are used an increasingly urgent matter.<sup>20</sup>

About 75% of all public LTC expenditures currently support nursing home care and the other 25% is used to provide LTC services in the community, mainly in-home services like home health care, personal care, homemaker, and respite services.<sup>21</sup> Nursing home care now costs \$60,000 to \$100,000 annually; assisted living costs \$25,000 to \$50,000 annually; and in-home care between \$10,000 and \$20,000 annually for those at risk of needing nursing level care.<sup>22</sup> Total LTC spending exceeded \$200

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14. *Id.* at 1; See AARP, *supra* note 8, at 3.

15. JOHNSON ET AL., *supra* note 1, at 6.

16. *Id.* at 13.

17. *Id.* at 21.

18. *Id.* at 25.

19. *Id.* at vi.

20. See *id.* at iv-vi.

21. KAREN TRITZ, CONG. RES. SERV., LONG-TERM CARE: TRENDS IN PUBLIC AND PRIVATE SPENDING 8 (2006), available at [https://www.policyarchive.org/bitstream/handle/10207/2798/RL33357\\_20060411.pdf?sequence=1](https://www.policyarchive.org/bitstream/handle/10207/2798/RL33357_20060411.pdf?sequence=1).

22. Genworth Financial, *Cost of Care Survey 2008: Home Care Providers, Adult Health Care Facilities, Assisted Living Facilities, and Nursing Homes* 4 (2008), available at [http://www.genworth.com/content/etc/medialib/genworth/us/en/Long\\_Term\\_Care](http://www.genworth.com/content/etc/medialib/genworth/us/en/Long_Term_Care).

billion in 2006, with Medicaid covering 49%, Medicare 19%, private insurance 7%, and out-of-pocket spending covering 21%.<sup>23</sup> Medicaid also paid over \$25 billion for home- and community-based services (HCBS), which, unlike nursing home care, are not entitlement services for those who meet stringent financial and level-of-need eligibility criteria.<sup>24</sup> About 25% of this \$25 billion was spent on those age sixty-five and older and most of the remaining 75% on the younger, developmentally-disabled population.<sup>25</sup> This much greater level of spending on HCBS programs for the developmentally disabled reflects the success of advocacy efforts on behalf of this population since the early 1970s in most states and at the national level.<sup>26</sup>

A recent study from the same office found that institutional and community LTC expenditures were much more balanced among young disabled Medicaid enrollees than their aged counterparts in 2002:

Over half of long-term care expenditures were for community-based services among younger disabled enrollees but less than 20% were for community-based care among those over 65; community-based service expenditures as a share of total LTC expenditures ranged from 50% for people under age 65, 31% for people between ages 65 and 74, 21% for people between ages 75 and 84, and 13% for those age 85 and older. Rates of community-based service utilization were higher but followed a similar pattern by age.<sup>27</sup>

The quote above reflects the greater priority that most states

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Par.14291.File.dat/37522%20CoC%20Brochure.pdf.

23. ENID KASSNER ET AL., AARP PUB. POL'Y INST., A BALANCING ACT: STATE LONG-TERM CARE REFORM 1 (2008), available at [http://assets.aarp.org/rgcenter/il/2008\\_10\\_ltc.pdf](http://assets.aarp.org/rgcenter/il/2008_10_ltc.pdf).

24. KAISER COMM'N ON MEDICAID AND THE UNINSURED, MEDICAID HOME AND COMMUNITY-BASED SERVICE PROGRAMS: DATA UPDATE 1 (2007), available at <http://www.kff.org/medicaid/upload/7720.pdf>.

25. KASSNER ET AL., *supra* note 23, at 7.

26. See Wiener, *supra* note 1, at 29.

27. AUDRA T. WENZLOW ET AL., U.S. DEP'T OF HEALTH AND HUMAN SERVS., A PROFILE OF MEDICAID INSTITUTIONAL AND COMMUNITY-BASED LONG-TERM CARE SERVICES USE AND EXPENDITURES AMONG THE AGED AND DISABLED USING MAX 2002: FINAL REPORT vi (2008), available at <http://aspe.hhs.gov/daltcp/reports/2008/profileMAX.pdf>.

have historically placed on the development of HCBS programs for younger disabled populations than for the frail elderly.

#### KNOWLEDGE- PRACTICE GAP IN LONG-TERM CARE

The fact that we spend so much more on nursing home care than community-based care for older individuals with LTC needs is the fiscal manifestation of the large gap between what we know and what we do in our publicly supported LTC.<sup>28</sup> This gap needlessly damages the lives of people who require LTC assistance and who would very much prefer to receive in their own homes or in a community-residential setting without the institutional constraints that characterize the vast majority of nursing homes.<sup>29</sup> However, the relatively limited level of public funding for HCBS alternatives to nursing home care in most states severely restricts their availability for those without the means to pay for them privately.<sup>30</sup>

Disabled persons of all ages vastly prefer home and community-based services to nursing home care or any other form of institutional care.<sup>31</sup> This preference is likely to be even stronger among members of the baby boom generation, whose LTC assistance needs will emerge over the next thirty years.<sup>32</sup> This clear preference for in-home- and community-based LTC services is matched by a growing body of research that demonstrates the relative cost-effectiveness of these services, if properly administered, and the success of a few states in developing an expansive array of community-based services over the last twenty years.<sup>33</sup>

"In 2006, only seven states spent 40% or more of their LTSS

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28. See TRITZ, *supra* note 21, at 8.

29. MATTHEW GREENWALD & ASSOCIATES, INC., AARP, THESE FOUR WALLS...AMERICANS 45+ TALK ABOUT HOME AND COMMUNITY 1 (2008), available at <http://assets.aarp.org/rgcenter/il/>.

30. See KASSNER ET AL., *supra* note 23, at vi.

31. MATTHEW GREENWALD & ASSOCIATES, INC., *supra* note 29, at 1.

32. JOHNSON ET AL., *supra* note 1, at 1.

33. See KASSNER ET AL., *supra* note 23, at v, Oregon and Washington State Profiles.

dollars on HCBS. . .”<sup>34</sup> Oregon, Washington, New Mexico, and Alaska now spend 50% or more on HCBS programs, which is a threshold most states passed years ago in their programs for the developmentally disabled.<sup>35</sup> Every state spending 40% or more on HCBS programs for the elderly is close to or below the national per capita age sixty-five plus LTC spending average.<sup>36</sup> This level of efficiency permits these states to meet a greater share of the need for LTC services than other states with less balanced LTC systems while still containing total LTC spending.<sup>37</sup>

Another recent analysis found that “[d]uration of nursing home spells was negatively associated with availability of community-based services in a state.”<sup>38</sup> “States with significant community-based programs tended to have a higher percentage of people using community-based services before entering nursing homes.”<sup>39</sup> “Oregon, a state with an extensive community-based waiver program, had the smallest percentage of enrollees with spells lasting longer than a year.”<sup>40</sup>

One of the reasons for the relatively slow growth of home and community-based long-term care for the frail elderly is the perception that community-based care is not cost-effective because it lacks the capacity to substitute for institutional care by diverting seriously impaired elderly from nursing home placement.<sup>41</sup> Several studies since 1995, however, indicate that

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34. *Id.* at 11.

35. *Id.* at 7.

36. *Id.*

37. See Glenn Mitchell et al., *The Relative Benefits and Cost of Medicaid Home and Community-Based Services in Florida* 46 GERONTOLOGIST 483, 484 (2006); see also KASSNER ET AL., *supra* note 23, at vi.

38. AUDRA T. WENZLOW ET AL., U.S. DEPT OF HEALTH AND HUMAN SERVS., MEDICAID FINANCED NURSING HOME SERVICES: CHARACTERISTICS OF PEOPLE SERVED AND THEIR PATTERNS OF CARE 2001-2002 v (2008), available at <http://aspe.hhs.gov/daltcp/reports/2008/mfNHserv.pdf>.

39. *Id.*

40. *Id.*

41. MARCUS HOLLANDER & NEENA CHAPPELL, HEALTH TRANSITION FUND, HEALTH CAN., FINAL REPORT ON THE NATIONAL EVALUATION OF THE COST-EFFECTIVENESS OF HOME CARE vii (2005), available at [http://www.coag.uvic.ca/resources/publications/reports/hollander\\_synthesis.pdf](http://www.coag.uvic.ca/resources/publications/reports/hollander_synthesis.pdf).



there is substantial potential for cost-effective and improved LTC in the expansion of well-designed and administered home and community-based programs.<sup>42</sup> These studies have found that by targeting certain services to high-risk recipients in increased quantities (number of nurse visits, hours of homemaker services, etc.), community programs tend to reduce nursing home use.<sup>43</sup> These findings have been used to help identify combinations of client and service characteristics that produce the most cost-effective results in terms of avoiding unnecessary institutionalization of impaired older people.<sup>44</sup>

A recent study of Medicaid-funded HCBS programs in Florida covering a five-year period from 2000 to 2005 found that all of them were cost-effective alternatives to nursing home care.<sup>45</sup> These programs ranged from one-quarter to one-half as expensive as the Medicaid nursing home program with impairment and caregiver resource profiles in other HCBS programs matching one-quarter to one-half of the nursing home new entrant population over the three-year study period.<sup>46</sup> Nursing home admission rates from the HCBS programs ranged from 9 to 27% over a thirty-six month follow-up period.<sup>47</sup> Many

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42. See JEFFREY A. RHOADES, *THE NURSING HOME MARKET: SUPPLY AND DEMAND FOR THE ELDERLY* 110-111 (Garland Publishers 1998); Vernon Greene et al., *Reducing Nursing Home Use through Community Long-Term Care: An Optimization Analysis*, 59 B J. GERONTOLOGY S259, S267 (1995); Brooke S. Harrow, et al., *How Costly Is It To Care for Disabled Elders in a Community Settings?* 35 GERONTOLOGIST 803, 803 (1995); Alan M. Jette et al., *How Does Formal and Informal Community Care Affect Nursing Home Use?* 50 B J. GERONTOLOGY S341, S341 (1995); Susan C. Miller et al., *Time to Nursing Home Admission for Persons with Alzheimer's Disease: The Effect of Health Care System Characteristics*, 53 B J. GERONTOLOGY S341, S341 (1998); APS HEALTHCARE, INC., *FAMILY CARE INDEPENDENT ASSESSMENT: AN EVALUATION OF QUALITY AND COST EFFECTIVENESS FOR CALENDAR YEAR 2003-2004* 78 (2005), available at <http://dhs.wisconsin.gov/ltcare/pdf/FCIndepAssmt2005.pdf>.

43. See RHOADES, *supra* note 42; Greene et al., *supra* note 42, at S267; Harrow et al., *supra* note 42, at 803; Jette et al., *supra* note 42, at S341; Miller et al., *supra* note 42, at S341; APS, *supra* note 42.

44. See RHOADES, *supra* note 42; Greene et al., *supra* note 42, at S267; Harrow et al., *supra* note 42, at 803; Jette et al., *supra* note 42, at S341; Miller et al., *supra* note 42, at S341; APS, *supra* note 42.

45. Mitchell et al., *supra* note 37, at 483.

46. See *id.* at 485.

47. Glenn Mitchell et al., *Florida Medicaid HCBS Waivers: A Comparison of Outcomes and Cost-Effectiveness* 1-62 (2007) at 40-41.

more participants died while in the HCBS programs (40% plus) than exited for a nursing home (20% or less).<sup>48</sup>

The mere availability, however, of HCBS programs is not sufficient to maximize opportunities to create a more efficient and cost-effective LTC system.<sup>49</sup> Methods of organizing, administering, and financing LTC are critical to achieving these goals and will be discussed at length later in the article.<sup>50</sup> The availability of HCBS programs, however, is a necessary, if not sufficient, condition for the development of more efficient and consumer-oriented LTC systems and for closing the gap between what we know and what we do in providing LTC services in most states.<sup>51</sup>

Many states are focusing less on closing the knowledge and practice gap in LTC and more on limiting the growth of their Medicaid-funded HCBS programs.<sup>52</sup> The survey found that the number of persons on waiting lists for waiver services was increasing.<sup>53</sup> "In 2006, 280,176 individuals were on waiting lists for ninety-three waivers in thirty-one states, up from 260,916 individuals in 2005 and 206,427 individuals in 2004."<sup>54</sup> The average length of time an individual spent on a waiting list ranged from thirteen months for aged/disabled and children's waivers to forty-two months for aged waivers."<sup>55</sup> As noted earlier, even with the declining impairment rates among the elderly and an overall improvement in health care status, the need for LTC is projected to increase by 50 to 100% over the next twenty-five years, which will put a great deal of pressure on Medicaid budgets in many states.<sup>56</sup> Creating more balanced LTC systems by expanding HCBS programs and containing the use

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48. *Id.* at 49.

49. See KASSNER ET AL., *supra* note 23, at ix.

50. *Id.* at ix-x.

51. *Id.* at v.

52. KAISER COMM'N ON MEDICAID AND THE UNINSURED, *supra* note 24, at 1.

53. *Id.* at 9.

54. *Id.* at 1.

55. *Id.*

56. JOHNSON ET AL., *supra* note 1, at 3.

of nursing home care is critical to meet the increased need for LTC services over the next two decades in a cost-effective manner.<sup>57</sup>

### BARRIERS TO CLOSING THE GAP

Creating more balanced LTC systems by expanding HCBS programs and containing the use of nursing home care will require that policy makers, advocates, and the media confront the several factors that have made change slow and limited the influence of the twenty-year-old Oregon and Washington model despite the growing evidence of public support for community-based care.<sup>58</sup> These factors include the following:

- Although public surveys show support for community-based alternatives to nursing home care, the issue has not achieved much political salience.<sup>59</sup> This reflects the fact that advocacy efforts for LTC reform have been weak to non-existent in most states and at the national level in comparison to the advocacy activities of the developmentally disabled community over the last thirty years.<sup>60</sup> Oregon is a major exception to this general tendency.<sup>61</sup> Several voluntary organizations, especially the Oregon Retired Teachers Association, played major roles in achieving passage of the landmark 1981 LTC legislation mandating the development of a home and community-based LTC system.<sup>62</sup> Increased advocacy efforts will be essential in offsetting the still powerful influence of the nursing home lobby in

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57. See KASSNER ET AL., *supra* note 23, at v.

58. See *id.* at 12-18.

59. ENID KASSNER, AARP PUB. POL'Y INST., CONSUMER DIRECTED HOME AND COMMUNITY-BASED SERVICES, FACT SHEET 1 (2006), available at [http://assets.aarp.org/rgcenter/il/fs128\\_cons\\_dir.pdf](http://assets.aarp.org/rgcenter/il/fs128_cons_dir.pdf); see Wiener, *supra* note 1, at 32.

60. See Wiener, *supra* note 1, at 29.

61. Interview with Richard Ladd, Dir. of the Div. of Senior and Disabled Adults (Oct. 1989).

62. *Id.*

most states in resisting a qualitative shift in the allocation of LTC resources.<sup>63</sup>

- Policy makers' fear of the "woodwork" effect continues to slow the expansion of HCBS programs in many states.<sup>64</sup> This fear is based on the perception that the HCBS programs are so much more appealing than nursing home care that their expansion will attract many new consumers and eventually make the LTC budget unsustainable.<sup>65</sup> The experience, however, in Oregon, Washington, and the few other states with relatively balanced LTC systems should assure policy makers that the costs of HCBS-oriented LTC systems can be effectively contained through uniform and rigorous needs assessment, service planning, care management, and expansion of community-based services that cost less than nursing home care.<sup>66</sup> Oregon, after twenty-five years of HCBS growth, spends \$225 annually per resident on LTC services, which is \$75 less than the national average and the eleventh lowest among the states.<sup>67</sup>
- A recent report on state LTC systems noted that: States like Oregon and Washington have demonstrated that they can serve more people at a lower cost per case by using noninstitutional settings whenever preferable and feasible. These states do serve more people with "unmet needs," absorbing them in the savings achieved through lower nursing home utilization and overcoming the fear of uncontrollable spending demands. Other states are just learning these lessons, which

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63. See John Rodgers, *Powerful Nursing Home Lobby Helped Craft Advantageous System, Officials Say*, NASHVILLE CITY PAPER, May 17, 2008, available at <http://www.nashvillecitypaper.com/news.php?viewStory=59175>; see also KASSNER ET AL., *supra* note 23, at 11.

64. KASSNER ET AL., *supra* note 23, at 16.

65. *Id.*

66. *Id.* at Washington and Oregon State Profiles.

67. *Id.* at 7.

may become more evident through the Money Follows the Person demonstration.<sup>68</sup>

- The aging services agency in most states is relatively weak in comparison to the power exercised by the state Medicaid office and tends to have relatively limited influence on Medicaid policy, either administratively or legislatively.<sup>69</sup> In Oregon and Washington, control over the Medicaid LTC budget has been lodged in the state aging services agencies, which gives them consolidated authority to make policy and budget decisions regarding the allocation of LTC resources.<sup>70</sup> This kind of organizational arrangement gives control of all public LTC to the aging network and is one of the major reasons Oregon and Washington have been able to make such dramatic changes in their LTC systems.<sup>71</sup>

State Medicaid offices and the Center for Medicare and Medicaid Services (CMS) have become more supportive of increased HCBS funding over the last twenty years, but they have not tended to strongly support the kind of qualitative shift in funding priorities carried out by Oregon and Washington.<sup>72</sup> In the absence of administrative consolidation and aging network control of all LTC resources, a few states have adopted managed LTC systems that fold all Medicaid LTC funds under a single capitated rate and empower the LTC agency and the consumer to make decisions about how these resources will be used.<sup>73</sup>

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68. *Id.* at 16.

69. See ROSALINE KANE, ET AL., CTRS. FOR MEDICARE AND MEDICAID SERVS., STATE LONG-TERM CARE SYSTEMS: ORGANIZING FOR REBALANCING 2-3 (2006), available at [http://www.cms.hhs.gov/NewFreedomInitiative/Downloads/Rebalancing\\_Topic\\_Paper\\_2.pdf](http://www.cms.hhs.gov/NewFreedomInitiative/Downloads/Rebalancing_Topic_Paper_2.pdf).

70. *Id.* at 7; See KASSNER ET AL., *supra* note 23, at Oregon State Profile.

71. See KANE ET AL., *supra* note 69, at 7.

72. See Wiener, *supra* note 1, at 29.

73. APS Healthcare, *supra* note 42, at 5; William G. Weissert et al., *Cost Savings from Home and Community-Based Services: Arizona's Capitated Medicaid Long-Term*

- The earlier mentioned influence of the nursing home industry has also been a factor in slowing the growth of HCBS programs.<sup>74</sup> Nursing homes receive about \$48 billion in Medicaid funding annually, which gives them considerable leverage with many governors, state legislatures, and Congress.<sup>75</sup> Their influence has declined over the last several years and some nursing home state associations have adopted more sophisticated lobbying and public relations strategies that include support for increased HCBS funding, but only after the annual budget needs of the nursing home industry have been met.<sup>76</sup> One indication of the continuing strength of the industry is that nursing home budgets continue to increase even as nursing home populations level off or decline.<sup>77</sup> However, some of this increase reflects efforts to meet the greater health and nursing needs of an increasingly greater percentage of patients with high acuity (more impaired and sicker) levels.<sup>78</sup>

Aging advocates should keep a close eye on recent changes in nursing home ownership patterns as large private equity firms (Carlyle, Blackstone) have begun to purchase nursing home corporations.<sup>79</sup> Given their vast financial resources, these firms may have more political influence than the traditional nursing home owners and the potential to exercise even more leverage over LTC

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Care Program, 22 J. HEALTH POL. POL'Y & L. 1329, 1329 (1997).

74. Rodgers, *supra* note 63; Robert Pear, *Nursing Home Lobbyists Had Access*, N.Y. TIMES, Apr. 23, 1997, available at <http://query.nytimes.com/gst/fullpage.html?res=9C05E6DD133EF930A15757C0A961958260>.

75. KAISER COMM'N MEDICAID AND THE UNINSURED, *supra* note 5, at 1.

76. See Bret Schulte, *A Bill Aims for Nursing Home Reform*, U.S. NEWS, Feb. 22, 2008, available at <http://www.usnews.com/articles/news/national/2008/02/22/a-bill-aims-for-nursing-home-reform.html>.

77. See AARP, *supra* note 8, at 3.

78. See *id.*

79. Charles Duhigg, *At Many Homes, More Profit and Less Nursing*, N.Y. TIMES, Sept. 23, 2007, available at [www.nytimes.com/2007/09/23/business/23nursing.html](http://www.nytimes.com/2007/09/23/business/23nursing.html).

public policy.<sup>80</sup> Even with the expansion of HCBS programs and the evolution of dramatically more balanced LTC systems, nursing homes will remain an essential part of the LTC continuum for those with advanced dementia and physical impairments, and their survival in substantially improved form (higher quality of care and of life for patients and caregivers) is critical to achieving and maintaining an appropriately balanced LTC system.<sup>81</sup> We cannot afford to allow the availability of high quality nursing home care to be sacrificed to the extraction of profits by private equity firms.

- A fifth factor that may prove to be a barrier to the growth of publicly funded HCBS programs in the future is the clamor in some quarters for private LTC insurance as an alternate to expanding public coverage for LTC services.<sup>82</sup> The effort to expand the use of private insurance is associated with the initiatives designed to restrict eligibility and funding for Medicaid supported LTC programs.<sup>83</sup> These initiatives include the recently successful Deficit Reduction Act of 2005 effort to extend the “lookback” period for asset transfers from three to five years.<sup>84</sup> The rationale for this initiative was the claim that many Medicaid LTC consumers are relatively affluent and deliberately impoverish themselves to become eligible for Medicaid by transferring large amounts of assets to relatives and

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80. See Pear, *supra* note 74; Rodgers, *supra* note 63.

81. See KASSNER ET AL., *supra* note 23, at vi.

82. MARK MERLIS, THE HENRY J. KAISER FAM. FOUND., PRIVATE LONG-TERM CARE INSURANCE: WHO SHOULD BUY IT AND WHAT SHOULD THEY BUY iii (2003), available at <http://www.kff.org/insurance/6072-index.cfm>.

83. See KAISER COMM'N ON MEDICAID AND THE UNINSURED, DEFICIT REDUCTION ACT OF 2005: IMPLICATION FOR MEDICAID (2006), available at <http://www.kff.org/medicaid/upload/7465.pdf>.

84. *Id.* at 4.

friends.<sup>85</sup> Some policy makers believed this claim even in the absence of any empirical support for its validity.<sup>86</sup> In fact, the most recent study indicates that the percentage of Medicaid LTC consumers who have transferred significant assets in the last five years is well under 5%.<sup>87</sup> This reflects the reality that most older people do not have many assets other than their own home.<sup>88</sup>

Our findings indicate that relatively few people who become Medicaid nursing home residents have transferred a substantial number of dollars. Asset transfer patterns were most common among nursing home residents who were “always private pay” meaning they did not receive Medicaid assistance to cover the cost of their nursing home care. Our analysis also estimated the maximum number of dollars that could possibly be recovered by Medicaid if all cases of transferred assets were deemed inappropriate and were collected as program savings and found that even the most aggressive pursuit of transferred assets would recover only about 1% of total Medicaid spending for long-term care.<sup>89</sup>

The effort by conservative opponents of publicly funded LTC, and health care more broadly, to exaggerate the wealth of the elderly is part of a larger campaign to increase the number of private LTC insurance policy holders.<sup>90</sup> Only about 9% of the sixty and older

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85. TIMOTHY WAIDMANN & KORBIN LIU, KAISER COMM'N ON MEDICAID AND THE UNINSURED, ASSET TRANSFER AND NURSING HOME USE: EMPIRICAL EVIDENCE AND POLICY SIGNIFICANCE 1 (2006), *available at* <http://www.kff.org/medicaid/upload/Asset-Transfer-and-Nursing-Home-Use-Issue-Brief.pdf>.

86. *Id.*

87. *Id.* at 5.

88. KAISER COMM'N ON MEDICAID AND THE UNINSURED, THE DISTRIBUTION OF ASSETS IN THE ELDERLY POPULATION LIVING IN THE COMMUNITY 5 (2005), *available at* <http://www.kff.org/medicaid/upload/The-Distribution-of-Assets-in-the-Elderly-Population-Living-in-the-Community-Issue-Paper.pdf>.

89. WAIDMANN & LIU, *supra* note 85, at 1.

90. *Id.* at 1; *see also* MERLIS, *supra* note 82, at 1-2.



population have LTC insurance, which currently covers about 5% of all LTC costs.<sup>91</sup> Conservative supporters of President Bush's "ownership society" see LTC insurance as an important vehicle for containing Medicaid costs over the next several decades, reducing the scope of the U.S. welfare state, forestalling any initiative to convert the means tested Medicaid LTC program into an entitlement (possibly under the Medicare program), forcing younger people to plan and provide for their retirement needs, and creating another major source of profits for the insurance industry.<sup>92</sup> Purchasing private LTC insurance, however, is simply not a prudent strategy for most people under age sixty and is largely unaffordable for those over age sixty-five.<sup>93</sup> According to an extensive analysis:

[T]hree out of four married couples could theoretically afford LTCI, using the affordability criteria adopted in a recent study by the American Council of Life Insurers. Yet, only one in five is adequately protected in all the other areas, including retirement savings, life insurance, health insurance, and disability insurance. The data suggest that a great many families who could afford LTCI are not preparing for retirement, or are not protected against life contingencies that could arise before expected retirement age. Most couples, if they have discretionary funds available, would probably be better advised to put them into savings or other forms of insurance before buying LTCI.<sup>94</sup>

Private insurance may become an increasingly

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91. National Bureau of Economic Research, *The Market for Long-Term Care Insurance*, <http://www.nber.org/aginghealth/winter05/w10989.html> (last visited Oct. 12, 2008).

92. See Charles Stein, *Ownership Society and Medicaid are an Unlikely Match*, THE BOSTON GLOBE, Mar. 20, 2005, available at [http://www.boston.com/business/personalfinance/articles/2005/03/20/ownership\\_society\\_and\\_medicare\\_are\\_an\\_unlikely\\_match?mode=PF](http://www.boston.com/business/personalfinance/articles/2005/03/20/ownership_society_and_medicare_are_an_unlikely_match?mode=PF). MERLIS, *supra* note 82, at iii, 1-2.

93. MERLIS, *supra* note 82, at x-xi.

94. *Id.* at iv.

important source of LTC funding over the next twenty years for the more affluent elderly in need of LTC, covering possibly as much as 20% of all LTC costs by 2025.<sup>95</sup> This trend could damper support for moving to a LTC entitlement program, but it is not likely to reduce the need for publicly supported LTC services, including HCBS programs, under the Medicaid program.<sup>96</sup> The vast majority of Medicaid LTC beneficiaries do not have the income needed to purchase LTC insurance nor many assets to protect with insurance.<sup>97</sup> This reality is not likely to change much over the next thirty years.<sup>98</sup> In fact many future retirees will be at substantially greater risk than current retirees of failing to maintain retirement income levels at 80% or more of their last wage earned while working.<sup>99</sup> The percentage of retirees failing to achieve this level of retirement income will increase from about 40% for the oldest baby boomers to over 60% for the youngest boomers by 2030.<sup>100</sup> This means that future retirees are likely to have less income to purchase LTC insurance than current retirees and are likely to be even more dependent on publicly provided LTC services.<sup>101</sup>

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95. *Id.*

96. See TRITZ, *supra* note 21, at 17; see also WIS. DEPT OF HEALTH SERVS., AN OVERVIEW OF WISCONSIN'S FAMILY CARE PROGRAM 1 (2008), available at <https://dhfs.wisconsin.gov/lcure/pdf/FCoverview.pdf>.

97. MERLIS, *supra* note 82, at x-xi.

98. Alicia Munnell, *Risk in Motion: The National Retirement Risk Index* 17 PUB. POL'Y & AGING REP. 16, 16 (2007).

99. *Id.*

100. See *id.*

101. See *id.* at 19; See also MERLIS, *supra* note 82, at 35.

## CLOSING THE GAP AND PREPARING TO MEET THE INCREASING NEED FOR LONG-TERM CARE SERVICES

### INTEGRATING ADMINISTRATIVE FUNCTIONS AND FUNDING SOURCES

The most immediate task confronting most states committed to creating a more balanced LTC system is to maximize current funding opportunities to expand HCBS programs in the same manner that Oregon and Washington have done for over twenty years (and a few other states more recently).<sup>102</sup> These states have used provisions within the Medicaid program (HCBS waivers) to build a growing array of HCBS programs and limit nursing home use.<sup>103</sup> Oregon and Washington have created integrated organizational structures at the state and service delivery levels to administer all public LTC resources—nursing home and HCBS funds.<sup>104</sup> This gives Oregon and Washington the capacity to use savings generated from reduced nursing home use to expand HCBS programs.<sup>105</sup>

A major factor identified in several recent assessments of state initiatives to create more balanced LTC systems was a consolidated state LTC agency that is responsible for administering all (nursing home and HCBS programs) LTC programs and has the capacity to move funds to HCBS programs as nursing home use declines.<sup>106</sup> Other factors

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102. See Joshua Wiener et al., *Home and Community-Based Services for Older Persons and Younger Adults with Disabilities in Seven States*, 23 HEALTH CARE FINANCING REV. 89, 89 (2002); see also KASSNER ET AL., *supra* note 23, at ix, Oregon and Washington State Profiles.

103. See KASSNER ET AL., *supra* note 23, at Oregon and Washington State Profiles.

104. KANE ET AL., *supra* note 69, at 17; KASSNER ET AL., *supra* note 23, at Oregon and Washington State Profiles.

105. See Wiener, *supra* note 102, at 89.

106. U.S. DEPT OF HEALTH AND HUMAN RES., ADMIN. ON AGING, CREATING MORE BALANCED LONG-TERM CARE INSURANCE: PREVIEWS OF CASE STUDIES ON THE ROLE OF THE NATIONAL AGING SERVICES NETWORK 4-6 (2003), available at <http://www.aoa.gov/prof/agingnet/HSSSI/FINAL%20Introduction%20to%20Case%20Studies%207-25-04.pdf>; STEVEN EIKEN, CTRS. FOR MEDICARE AND MEDICAID SERVS., TECHNICAL ASSISTANCE GUIDE TO ASSESSING STATE LONG-TERM CARE

include single-entry points that facilitate accurate and timely assessment of needs, eligibility determination, and prompt access to appropriate services; nursing home supply controls such as certificate of need (CON); systematic mechanisms to move nursing home residents into community-based programs (nursing home transition program); extensive and continuing HCBS infrastructure development, including a continuum of community-residential options and participant directed programs (consumer directed care); and systematic efforts to measure and ensure quality in community-based as well as nursing home programs.<sup>107</sup> A consolidated state LTC agency appears to be the most important single factor in facilitating the development of balanced LTC systems, in part by making the other factors associated with rebalancing more achievable.<sup>108</sup>

Only two states (Oregon and Washington) have fully integrated control over all LTC programs and funds, including the Medicaid Nursing Home Program in their state aging agencies.<sup>109</sup> In other states, the management of LTC programs is split between departments of aging/senior services (home and community-based programs) and the departments housing the Medicaid program (nursing homes and some home care).<sup>110</sup> The department that houses Medicaid, in effect, controls on average 70 to 80% or more of all LTC resources.<sup>111</sup>

An alternative method of integrating LTC authority that does not require a single state agency that has complete control over policy and all LTC funds is to develop a managed LTC program at the local or regional level and operate it under a capitated rate based on all major LTC funding sources, including

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SYSTEMS iii (2006), available at [http://www.cms.hhs.gov/newfreedominitiative/downloads/ta\\_guide.pdf](http://www.cms.hhs.gov/newfreedominitiative/downloads/ta_guide.pdf).

107. U.S. DEPT OF HEALTH AND HUMAN RES., *supra* note 106, at 4-6; KANE ET AL., *supra* note 69, at iv; EIKEN, *supra* note 106, at iii.

108. U.S. DEPT OF HEALTH AND HUMAN RES., *supra* note 106, at 4-6; KANE ET AL., *supra* note 69, at iv; EIKEN, *supra* note 106, at iii.

109. KASSNER ET AL., *supra* note 23, at Oregon and Washington State Profiles.

110. *Id.* at State Profiles.

111. *Id.*

Medicaid nursing home funds.<sup>112</sup> The capitation rate could be constructed through negotiation between representatives of the aging network, under the leadership of the state aging unit, and the state's Medicaid office, and incorporated into a contract.<sup>113</sup> Wisconsin has taken this approach with the Wisconsin Family Care Program, and Arizona has operated a Medicaid managed LTC system statewide for several years.<sup>114</sup> Texas, Minnesota, and Florida also have substantial managed LTC initiatives underway on a county or regional basis.<sup>115</sup>

The Wisconsin Family Care Program has two components—aging and disability resource centers and care management organizations.<sup>116</sup> The resource centers serve as single-entry points into the LTC system that provide information, counseling, access to all LTC services and providers, and preventive healthcare and early intervention services.<sup>117</sup> An important feature of the resource centers is their capacity to serve not only Medicaid-eligible consumers, but also private-pay consumers and their families.<sup>118</sup> Providing information and assistance to the non-Medicaid population is an important element of any strategy to change LTC systems.<sup>119</sup> A program that assists private-pay consumers holds great potential for empowering all older people to make informed decisions about their care choices and containing public and private costs.<sup>120</sup>

Not many states have a comprehensive, integrated single-entry point system for LTC services for the elderly comparable to the Wisconsin Family Care Resource Centers.<sup>121</sup> In order to increase the number of states with integrated single-entry point

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112. Weissert et al., *supra* note 73, at 1329.

113. *Id.*; APS Healthcare, *supra* note 42, at 5.

114. Weissert, *supra* note 73, at 1329; APS Healthcare, *supra* note 42, at 5.

115. KASSNER ET AL., *supra* note 23, at Texas, Minnesota, and Florida State Profiles.

116. Wiener, *supra* note 102, at 97.

117. *Id.*

118. WIS. DEP'T OF HEALTH SERVS., *supra* note 96, at 2.

119. *See id.*

120. *See id.*

121. KASSNER ET AL., *supra* note 23, at State Profiles.

systems, since 2003 the Administration on Aging and the Centers for Medicare & Medicaid Services (CMS) funded over forty-five states to develop Aging and Disability Resource Centers that are based on the Wisconsin Family Care Resource Center model.<sup>122</sup> These centers are designed to provide integrated access to a comprehensive array of information and services, thereby increasing consumer awareness of all LTC options and increasing consumer control over the LTC decision-making process.<sup>123</sup>

The second major component of the Wisconsin Family Care Program is the care management organizations (CMOs).<sup>124</sup> The CMOs are capitated, managed care organizations for all LTC services, including nursing home care.<sup>125</sup> The capitation rate includes Medicaid (nursing home and home and community-based services), state, and county funds consolidated into single monthly payments that average about \$2,000 a month.<sup>126</sup> The capitation rate constitutes a strong incentive to keep consumers in the community (nursing home care costs much more) and to create a seamless system in which individuals' needs dictate the services provided, rather than program eligibility criteria.<sup>127</sup>

A comprehensive evaluation of Family Care found that the program has generated significant savings and high consumer satisfaction, and changed the kinds of services provided.<sup>128</sup> The CMOs purchased (or prompted their members to purchase, in the case of primary and acute care) more of some lower-cost services and less of other higher-cost services, with the result that the cost of the total package was lower for the Family Care members than for a matched comparison sample of individuals receiving Medicaid-funded services who were not in the Family

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122. Wiener, *supra* note 1, at 29.

123. WIS. DEP'T OF HEALTH SERVS., *supra* note 96, at 2-4.

124. *Id.*

125. Wiener, *supra* note 102, at 97.

126. Diane Justice, *Promising Practices in Long-Term Care Systems Reform: Wisconsin Family Care* (2003) 1-22, prepared for U.S. Dep't of Health and Human Servs., Ctrs. for Medicare and Medicaid Servs. at 17.

127. Weissert et al., *supra* note 73, at 1329.

128. APS Healthcare, *supra* note 42, at 90-91.

Care Program.<sup>129</sup> For example, average individual monthly costs at the end of the study period for a Milwaukee County frail elder's care in a community-based residential facility (CBRF) was \$462 more than that spent for CBRF care for the comparison group.<sup>130</sup> On the other hand, average individual monthly costs for nursing facility care of frail elders served by the Milwaukee CMO were \$1,363 less than those for frail elders in the matched comparison group at the end of the study period.<sup>131</sup> These shifts in services are a direct result of the flexibility in managing resources through the Family Care benefit package.<sup>132</sup> As a result of these findings, the Legislature decided in 2006 to extend the program statewide.<sup>133</sup>

This approach may not work everywhere and better ideas may emerge. Managed long-term care is not the only way to integrate LTC resources and create vehicles for making LTC more efficient and consumer-responsive.<sup>134</sup> However, managed long-term care appears to be one of the best methods at hand and offers considerable hope for overcoming the growing discrepancy between increasing needs and scarce resources and reforming our LTC system by taking full advantage of the resources available in the aging network to close the gap between what we know and what we do in LTC.<sup>135</sup> This approach could also help the aging network prevent the takeover of the publicly supported LTC system by for-profit managed care organizations.<sup>136</sup>

Proprietary HMO-based managed LTC programs are now operating in Texas (STAR Plus program), Florida (Nursing

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129. *Id.* at 17.

130. *Id.*

131. *Id.* at 16.

132. *Id.* at 97.

133. S. 653 (WIS. 2005) (codified at WIS. STAT. §§ 46.27-46.285) (2005).

134. Wiener, *supra* note 1, at 29.

135. See generally WIS. COUNCIL ON LONG-TERM CARE, PRINCIPLES TO GUIDE LONG-TERM CARE REFORM IN WISCONSIN (2005), available at <http://www.wcltc.state.wi.us/pdf/LTCRprinciples1005.pdf>.

136. See Maureen Glabman, Managed Care, *Health Plan Foundations: How Well Are They Spending the Money?*, <http://www.managedcaremag.com/archives/0808/0808.foundations.html> (last visited Sept. 11, 2008).

Home Diversion) and Arizona (ALTCS) on an extensive scale and to a more limited extent in a few other states.<sup>137</sup> As described earlier, an evaluation of HCBS waiver programs in Florida found that the HMO-dominated managed LTC program (Diversion) is a relatively cost-effective alternative to nursing homes but less cost-effective than the other aging network-based HCBS waiver-funded programs.<sup>138</sup>

A 1997 evaluation of the Arizona managed LTC System (ALTCS) found that the program created a far more balanced LTC system (50% HCBS) and had effectively contained public LTC costs.<sup>139</sup> Before 1997, most of the participating HMOs were non-profit, public agencies, including public health agencies in Phoenix and Tucson.<sup>140</sup> Since then, proprietary HMOs have become dominant in the ALTCS program.<sup>141</sup>

A few states (Minnesota, Massachusetts, and Wisconsin) have developed Medicare and Medicaid managed care programs designed to integrate acute, chronic, and LTC services.<sup>142</sup> These initiatives are based on lessons learned from the PACE Medicare/Medicaid program that was created over

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137. Texas Health and Human Servs. Comm'n, <http://www.hhsc.state.tx.us/Starplus/Overview.htm> (last visited Sept. 9, 2008); OFFICE OF PROGRAM POLICY ANALYSIS & GOV'T ACCOUNTABILITY, THE NURSING HOME DIVERSION PROGRAM HAS SUCCESSFULLY DELAYED NURSING HOME ENTRY, Report No. 06-45 (2006), available at <http://www.oppaga.state.fl.us/reports/pdf/0645rpt.pdf>; Arizona Health Care Cost Containment System: Arizona Long-Term Care System (ALTCS), <http://www.ahcccs.state.az.us/Services/Programs/ALTCS.asp> (last visited Sept. 9, 2008).

138. Glenn Mitchell, II et al., *The Relative Benefits and Cost of Medicaid Home- and Community-Based Services in Florida*, 46 GERONTOLOGIST 483, 491 (2006).

139. See William G. Weissert et al., *Cost Savings from Home and Community-Based Services: Arizona's Capitated Medicaid Long-Term Care Program*, 22 J. HEALTH POL., POL'Y & L. 1329, 1337, 1346 (1997).

140. *Id.* at 1346.

141. Richard L. Peck, "Elderly Population Growth Is Not Being Acknowledged. . .", 44 NURSING HOMES 44, 44 (1996).

142. Minn. Dep't of Health: Managed Care Regulation, <http://www.health.state.mn.us/divs/hpsc/mes/index.htm> (last visited Sept. 9, 2008); Health and Human Servs., MassHealth, <http://www.mass.gov/?pageID=eohhs2agencylanding&L=4&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=MassHealth&sid=Eeohhs2> (last visited Sept. 9, 2008); OFFICE OF THE COMM'R OF INSURANCE, STATE OF WIS., CONSUMER'S GUIDE TO MANAGED CARE HEALTH IN WISCONSIN 6 (2008), available at [http://www.oci.wi.gov/pub\\_list/pi-044.pdf](http://www.oci.wi.gov/pub_list/pi-044.pdf).



twenty years ago and now operates in over twenty states.<sup>143</sup> The relative cost-effectiveness of these relatively early-stage programs has not yet been clearly established, but their potential is very promising.<sup>144</sup> Most states, however, may be better served by integrating their LTC systems before implementing Medicare and Medicaid managed care programs.<sup>145</sup>

One of the best ways for the aging network to play this role is to create a managed LTC system similar to the Wisconsin Family Care Program that integrates LTC funds (state and federal) and services (community-based and nursing home care) in advance of any effort to integrate long-term care and acute care.<sup>146</sup> This approach would strengthen the aging network's ability to use managed care to expand community-based services (shifting resources from institutional to community-based programs) and to prepare mechanisms for "downward substitutions" when more fully integrated systems (long-term care and acute care) are implemented.<sup>147</sup>

#### *EXPANDING COMMUNITY-BASED PROGRAMS*

Organizational innovations and financing strategies based on the more expansive use of Medicaid-waiver options and new

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143. JOSHUA M. WIENER & JASON SKAGGS, PUB. POL'Y INST. AARP, CURRENT APPROACHES TO INTEGRATING ACUTE AND LONG-TERM CARE FINANCING AND SERVICES 14 (1995); Ctrs. for Medicare and Medicaid Servs., PACE Expansion, <http://www.dhh.louisiana.gov/offices/miscdocs/docs-296/CMS%20Medicare%20Review%209-14-06%20meeting.pdf> (last visited Sept. 9, 2008).

144. COMM'RS OFFICE, MINN. DEP'T OF HEALTH, ANNUAL QUALITY IMPROVEMENT REPORT ON THE NURSING HOME SURVEY PROCESS 6 (2007); DIV. OF HEALTH CARE FINANCE AND POL'Y, HEALTH CARE IN MASSACHUSETTS: KEY INDICATORS 1 (2008), available at [http://www.mass.gov/Eeohhs2/docs/dhcfp/r/pubs/08/key\\_indicators\\_0808.pdf](http://www.mass.gov/Eeohhs2/docs/dhcfp/r/pubs/08/key_indicators_0808.pdf); BUREAU OF MANAGED HEALTH CARE PROGRAMS, DEP'T OF HEALTH AND FAMILY SERVS., STATE OF WIS., EXTERNAL QUALITY REVIEW, 25-26 (2007), available at [http://dhs.wisconsin.gov/medicaid7/reports\\_data/quality\\_reports/pdfs/eqr2007.pdf](http://dhs.wisconsin.gov/medicaid7/reports_data/quality_reports/pdfs/eqr2007.pdf).

145. LARRY POLIVKA, WHITE HOUSE CONFERENCE ON AGING, COORDINATED SOCIAL AND HEALTH SERVICES THAT GIVE THE ELDERLY THE MAXIMUM OPPORTUNITY TO AGE IN PLACE, 1-6 (June 13, 2005).

146. Letter from Manice Mueller, Auditor, State of Wis. to Senator Roessler and Representative Jeskewitz, Joint Legislative Audit Comm., State of Wis. (July 15, 2003), available at [www.legis.state.wi.us/lab](http://www.legis.state.wi.us/lab).

147. *See id.*

administrative structures should be designed to create a wider range of HCBS programs.<sup>148</sup> A more expansive array of HCBS options should include consumer-directed care programs like the Cash and Counseling program, and community-residential programs like assisted living, especially smaller facilities (sixteen or fewer beds) and adult foster homes (Family Care Homes).<sup>149</sup>

The Cash and Counseling program gives a consumer control of funds that a consumer can use to organize the kind of LTC assistance the consumer needs in the way he or she chooses, usually by paying the consumer's caregiver who is most often a relative or friend.<sup>150</sup> An extensive evaluation of the Robert Wood Johnson Foundation-supported cash and counseling demonstration projects in Arkansas, New Jersey, and Florida found that the projects were generally cost-effective in comparison to agency-directed in-home programs, especially in terms of caregiver and consumer satisfaction levels and reduced nursing home use.<sup>151</sup>

The California In-Home Supportive Services (IHSS) Program is the largest and oldest consumer-directed care program in the U.S.<sup>152</sup> The program, which is over thirty years old, receives over \$500 million dollars annually and serves over 200,000 consumers, of whom about half are age sixty-five and older.<sup>153</sup> The program is designed to allow payments to a wide

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148. SHEILA P. BURKE, NAT'L ACAD. OF SOC. INS., *DEVELOPING A BETTER LONG-TERM CARE POLICY: A VISION AND STRATEGY FOR AMERICA'S FUTURE* iii-iv (2005), available at [http://www.nasi.org/usr\\_doc/Developing\\_a\\_Better\\_Long-Term\\_Care\\_Policy.pdf](http://www.nasi.org/usr_doc/Developing_a_Better_Long-Term_Care_Policy.pdf).

149. Stephen M. Golant, *The Future of Assisted Living Residences: A Response to Uncertainty*, in *THE ASSISTED LIVING RESIDENCE: A VISION FOR THE FUTURE* 1,1 (Stephen M. Golant & Joan Hyde eds., 2008); RANDALL BROWN, MATHEMATICAL POL'Y RESEARCH, INC., *CASH AND COUNSELING: IMPROVING THE LIVES OF MEDICAID BENEFICIARIES WHO NEED PERSONAL CARE OR HOME AND COMMUNITY-BASED SERVICES* xvi (2007), available at <http://www.cashandcounseling.org/resources/20070910-145713/Crosscutting.pdf>.

150. Brown, *supra* note 149, at 3.

151. *Id.* at 96; Stacy B. Dale & Randall Brown, *Reducing Nursing Home Use through Consumer-Directed Personal Care Services* 44 *MEDICAL CARE* 760, 765 (2006).

152. Rtz Associates, Inc., *The State of IHSS Health Benefits in California: A Survey of Counties* 1 (2005), available at [http://www.rtzassociates.com/publications/issue\\_brief2005.pdf](http://www.rtzassociates.com/publications/issue_brief2005.pdf).

153. A. E. Benjamin et al., *Comparing Consumer-directed and Agency Models for*

range of caregivers, including family and agency-managed caregivers.<sup>154</sup> These facts make IHSS the most important initiative in consumer-directed care in the U.S. and the program from which we may have the most to learn about the feasibility and desirability of this approach to LTC for the frail elderly.<sup>155</sup>

A comprehensive evaluation of the IHSS program was completed in 1997.<sup>156</sup> The study found that on virtually every client outcome measure, the consumer-directed model clearly outperformed the agency-directed model.<sup>157</sup> Under even the most demanding conditions, such as severity of disability and differential availability of informal supports, the consumer-directed model of service provision consistently yielded superior results on measures of client satisfaction with services, personal empowerment, and quality of life.<sup>158</sup> In summarizing the results of the IHSS evaluation:

Critics of consumer-directed models of service delivery have expressed concerns about client safety under this model and have generally taken the view that consumer direction should be restricted to a minority of clients (primarily younger adults) who social workers judge to be capable of hiring, firing and giving direction to their workers. This study provides no evidence in support of restricting availability of the consumer-directed model. Critics have also questioned the appropriateness of allowing public program clients to hire family members as providers. This study's findings support the option of hiring family members as providers because the data indicate that, on average, family providers are more likely to provide a higher quality of service than unrelated workers.<sup>159</sup>

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*Providing Services at Home* 35 HEALTH SERV. RESEARCH 351, 354, 356 (2000); Rtz Associates, Inc., *supra* note 152, at 1.

154. Benjamin, *supra* note 153, at 354.

155. PAMELA DOTY, U.S. DEP'T HEALTH AND HUMAN SERV., IN-HOME SUPPORTIVE SERVICES FOR THE ELDERLY AND PROFESSIONAL MANAGEMENT MODELS OF SERVICE DELIVERY 28 (1999), available at <http://aspe.hhs.gov/daltcp/reports/ihss.htm>.

156. Benjamin, *supra* note 153, at 351.

157. *Id.* at 360.

158. *Id.* at 362-63.

159. DOTY, *supra* note 155, at 4.

Over forty states now have some version of consumer-directed care, including twelve states with new cash and counseling programs.<sup>160</sup> But the percentage of publicly supported LTC recipients in consumer-directed care programs is still very small (probably less than 5%). Consumer-directed LTC programs have the potential not only to improve the quality of care and life of LTC consumers, but also to help address the emerging shortage of LTC workers that could become severe with the aging of the baby boomers.<sup>161</sup>

The elephant in the room receiving relatively little attention is the issue of workforce. Long term care is a uniquely hands-on, personal service provided by human beings. While we can hope for technological fixes, the personal nature of the service makes that difficult. We need people to provide long term care. Currently, we face workforce shortages, with high turnover resulting in lack of continuity of care and numerous vacancies limiting expansion and improvement of services (Stone and Wiener, 2001). Given the low wages, lack of benefits, and job structure for certified nurse assistants, this is not surprising, but the situation can only get worse as the demographics change. The ratio of persons age 22-64 (the working-age population) to the population age 85 and over (the population in need of long-term care) is projected to decline from 34.6 in 2005 to 11.4 in 2050 (U.S. Bureau of the Census, 2004). This demographic change will have enormous impacts on the ability to provide services, what those services will cost, and the quality of those services. Unless we find ways to entice more people to provide long term care services and find a "we" to improve the quality of that care, we will face problems that will dwarf our current difficulties.<sup>162</sup>

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160. THE ENCYCLOPEDIA OF ELDER CARE: THE COMPREHENSIVE RESOURCE ON GERIATRIC AND SOCIAL CARE, 162 (Elizabeth A. Capezuti, Eugenia L. Singer & Mathy D. Mezey eds., 2007).

161. Lawrence Polivka & Jennifer Salmon, *Autonomy and Consumer Empowerment: Making Quality of Life the Organizing Principle for Long-Term Care Policy*, in MENTAL WELLNESS IN AGING: STRENGTHS-BASED APPROACHES 15, 19 (Judah L. Ronch & Joseph A. Goldfield eds., 2003).

162. Wiener, *supra* note 1, at 32.

Assisted living has grown enormously since 1990 (one million assisted living residents in 2007), but the availability of publicly supported assisted living is still very limited in most states. Oregon and Washington have long demonstrated the capacity of assisted living to help contain nursing home use and provide a high quality of LTC assistance to impaired persons who can no longer remain in their own homes.<sup>163</sup> The demographic characteristics (fewer children and spouses) and lifestyle preferences (independence and autonomy) are likely to make assisted living a highly preferred option for the baby boomers, regardless of their individual financial resources.<sup>164</sup>

Adult Foster Care is a largely neglected LTC resource in most states, even though Oregon and Washington long ago demonstrated its utility as an essential part of both the publicly and privately funded LTC system.<sup>165</sup> Oregon now has over 6,000 adult foster beds, 70% of which are filled by private-pay residents.<sup>166</sup> An evaluation in Washington found that residents of foster homes and small assisted living facilities were highly satisfied with their care arrangements, which were among the least expensive of LTC programs.<sup>167</sup>

The instructive examples of Oregon, Washington, and a few other states with relatively balanced LTC systems, and the research supporting the relative cost-effectiveness of HCBS programs and the public preferences for them, may not be enough to speed up the creation of community-based LTC systems to the extent needed in the face of an aging

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163. Larry Polivka & Jennifer R. Salmon, *Assisted Living: What It Should Be and Why*, in THE ASSISTED LIVING RESIDENCE: A VISION FOR THE FUTURE 397, 404 (Stephen M. Golant & Joan Hyde eds., 2008); Assisted Living Federation Of America, *Guide to Choosing an Assisted Living Residence*, available at <http://www.alfa.org/files/public/ALFAchecklist.pdf>.

164. Golant, *supra* note 149, at 22, 25; NCB Capital Impact, *What is Affordable Assisted Living?*, <http://www.ncbcapitalimpact.org/default.aspx?id=60> (last visited Oct. 11, 2008).

165. Polivka & Salmon, *supra* note 163, at 404.

166. Rosalie A. Kane et al., *Adult Foster Care for the Elderly in Oregon: A Mainstream Alternative to Nursing Homes?* 81 AM. J. PUB. HEALTH 1113, 1113 (1991).

167. Susan C. Hedrick et al., *Resident Outcomes of Medicaid-Funded Community Residential Care*, 43 GERONTOLOGIST 473, 480 (2003).

population.<sup>168</sup> The pace needs to be much faster over the next ten years than it has been for the last twenty years.<sup>169</sup> Aging and LTC reform advocates who support the rapid expansion of HCBS programs should form advocacy coalitions with labor unions, especially those representing caregiving workers like Service Employees International Union, retiree organizations (like state retired teachers associations), and other organizations of retired professionals.<sup>170</sup>

### *A LITIGATION STRATEGY FOR LONG-TERM CARE REFORM*

LTC advocacy groups and coalitions should seriously consider pursuing a legal approach to creating more effective and humane LTC systems; this approach should be based on the United States Supreme Court's *Olmstead v. L.C.* decision, its interpretation of Title II of the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act.<sup>171</sup> These laws and the *Olmstead* decision would appear to require coverage of, as appropriate, LTC services in the most integrated (non-institutional) setting and avoid providing unnecessary and unwanted LTC in institutional settings.<sup>172</sup> In Florida, where a suit supported by AARP has been filed, the MDS data indicates that 26% of nursing home residents (half of them Medicaid supported) want to move back into the community.<sup>173</sup> A recent analysis of Minimum Data Set (MDS) data from each state found that based on very conservative criteria (no impairment in four late developing ADLs), at least ten to 15% of nursing home

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168. ENID KASSNER, ET AL., AARP PUB. POL'Y INST., *A BALANCING ACT: STATE LONG-TERM CARE REFORM* viii (2008).

169. *Id.*

170. Service Employees International Union, Long-Term Care Reform, [http://www.seiu.org/longterm/issues/ltc\\_reform.cfm](http://www.seiu.org/longterm/issues/ltc_reform.cfm) (last visited Oct. 11, 2008); AARP Leads Fight for Long-Term Care Reform, <http://www.aarp.org/aarp/articles/mi-LTC-reform.html> (last visited Oct. 11, 2008).

171. 42 U.S.C. § 12101 (a)(2) (2005); 29 U.S.C. § 794 (a) (1999); *Olmstead v. L.C.*, 138 F.3d 893, 900 (11th Cir. 1999).

172. 42 U.S.C. 12101 (b) (2006); 29 U.S.C. § 794 (a) (2006); *Olmstead*, 138 F.3d at 897.

173. *AARP v. EEOC*, 489 F. 3d 558 (3d Cir. 2007).

residents do not have a level of impairment sufficient to justify nursing home placement.<sup>174</sup>

The *Olmstead* decision has potentially major implications for LTC of the frail elderly, especially those receiving Medicaid and general-revenue funded services.<sup>175</sup> As noted earlier, about 80% of these funds are currently spent on nursing home care.<sup>176</sup> An early analysis of state and federal court cases and decisions interpreting *Olmstead* indicates that:

- . . . arbitrary expenditure caps on covered home and community services that, when surpassed, result in institutionalization or re-institutionalization would violate the ADA . . . [and] a state must be able show that additional services would amount to a fundamental alteration and may not require an individual to prove that community care is reasonable.
- [Courts may impose] outer limits on the number of days a state has to put together an appropriate community care program for an individual who[] . . . is inappropriately institutionalized and who desires community care.
- The individuals protected by the *Olmstead* ruling . . . are in institutions and [] could be appropriately cared for in the community and also in the community and who risk institutionalization unless they receive appropriate care.
- States [must] ensure that nursing home diversion programs properly avert institutionalization for potential residents through the provision of appropriate community care. Thus, while the state need not institute a nursing home diversion

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174. See Vincent Mor et al., *Prospects for Transferring Nursing Home Residents to the Community* 26 HEALTH AFFAIRS 1762, 1764 (2007).

175. Sara Rosenbaum, AARP PUB. POL'Y INST., *OLMSTEAD V. L.C.: IMPLICATIONS FOR OLDER PERSONS WITH MENTAL AND PHYSICAL DISABILITIES* i (2000), available at [http://assets.aarp.org/rgcenter/health/2000\\_21\\_disabilities.pdf](http://assets.aarp.org/rgcenter/health/2000_21_disabilities.pdf).

176. KASSNER ET AL., *supra* note 168, at 6.

program, if it does so, it must fully fund the program it offers.<sup>177</sup>

The HHS *Olmstead* planning guidelines specify that the states should be prepared to respond to the following issues vis-à-vis their long-term care Medicaid program for the frail elderly:

- Does the state's Medicaid home and community waiver program reach older individuals as well as children and young adults?
- Does the state Medicaid plan [and the HCB waiver programs] provide coverage for the types and range of services identified by experts as important to the successful community integration of older persons with disabilities?
- [D]oes the state screen nursing home and other institutional residents to determine appropriateness of their placements?
- In the case of older persons . . . without . . . informal caregiver arrangements, what resources are available . . . to help meet the cost of community housing, particularly assisted living arrangements?
- Does the process include persons who are knowledgeable about the design of community-based programs and services for older persons with disabilities?<sup>178</sup>

*Olmstead*-oriented planning initiatives should be used by advocates and policy experts to make the case for a rapid expansion of home and community-based alternatives to nursing homes, with a special focus on allowing consumers to pay caregivers by funding programs like those described in an earlier section of this paper, especially the California IHSS program.<sup>179</sup> These programs seem to be extraordinarily compatible with the thrust of the *Olmstead* decision—how better to integrate the frail elderly into mainstream community life

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177. Rosenbaum, *supra* note 175, at ii-iii.

178. *Id.* at 17.

179. DOTY, *supra* note 155, at 4, 9.



than by allowing them to make as many decisions as possible about how to deal with their own LTC needs. This perspective has received substantial support through federal policy in the form of CMS programs and congressional legislation over the past several years, but most states have been slow to respond in terms of changing their LTC policies for the elderly by expanding the provision of consumer-directed care.<sup>180</sup>

#### AN ETHICAL FRAMEWORK FOR LONG-TERM CARE REFORM

The inherently ethical implications of *Olmstead* have not yet led to a comprehensive consideration of the ethical aspects of the gap between what we know and what we do in providing LTC services for the frail elderly.<sup>181</sup> While we need to continue to conduct research studies on LTC options, we should not expect that the results of research alone will create sufficient conditions for a profound change in the direction of LTC policy.<sup>182</sup> Such change will require a collective change of heart that is fundamentally dependent on the creation of a clear moral vision for LTC.<sup>183</sup> Research can help us identify the most efficient and consumer-responsive methods of achieving policy priorities guided by a moral vision.<sup>184</sup> Research is not, however, a substitute for the kind of moral reasoning we need to undertake as a community and as an aging society.<sup>185</sup>

The developmentally disabled (DD) and disabled adult (DA) communities have achieved a far more diversified, consumer-oriented community-based LTC system than we have been able to create over the last twenty-five years for the frail elderly.<sup>186</sup> Research comparing the relative cost-effectiveness of home and community-based versus institutional care for the DD

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180. KASSNER ET AL., *supra* note 168, at vii.

181. Rosenbaum, *supra* note 175, at iii-iv.

182. KASSNER ET AL., *supra* note 168, at xi.

183. Polivka & Salmon, *supra* note 161, at 16.

184. KASSNER ET AL., *supra* note 168, at 12.

185. *Id.*

186. Elias Cohen, *The Elderly Mystique: Constraints on the Autonomy of the Elderly with Disabilities* 28 GERONTOLOGIST 24, 26-27 (1988).

and DA populations is not qualitatively more extensive or conclusive than the research results now available on the frail elderly population; yet, the absence of complete certainty did not keep the DD and DA communities from transforming their LTC systems over the last twenty-five years by pressing for more humane and autonomy-enhancing LTC programs.<sup>187</sup>

This discrepancy has been attributed to differences in the kinds of physical or cognitive impairments experienced by these populations, differences in the extent of family involvement and commitment, and the level of self-advocacy. These differences are less important than the fact that the aging research and advocacy community does not have a coherent, compelling moral vision and ethical theory comparable to the developmental/normalization model that has guided DD policy and practice since the early 1970s, or the commitment over the same period to autonomy and self-direction that has driven the development of policies and programs for younger disabled adults.<sup>188</sup>

The DD community has long benefited from well-organized, intensive advocacy initiatives at the federal and state levels.<sup>189</sup> Historically, a moral and ethical framework (a theory of rights and obligations) grounded in the normalization principle have guided these initiatives.<sup>190</sup> From the perspective of the normalization principle, developmentally disabled individuals may be different from others, but these differences are not viewed negatively; society must be prepared to support and nurture them.<sup>191</sup> This represents a major framework for understanding and treating developmental disabilities.<sup>192</sup>

In the case of disabled adults, advocates in the independent living movement have largely recast disability as an oppressed minority group status that has allowed the disabled to advocate

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187. *Id.* at 30.

188. *Id.*

189. *Id.* at 26-27.

190. *Id.* at 27.

191. *Id.*

192. *Id.*

for a more responsive and supportive environment and to generate sources of self-empowerment for the disabled adults.<sup>193</sup> By comparing the independent living orientation of non-elderly disabled with the perception of dependency imposed upon the elderly disabled, impairment is, in substantial part, socially constructed: "[W]e speak of the disabling environment. This concept places the locus of disability not solely within individuals who have impairments but also in the social, economic, and political environment. By this argument, people are impaired but the environment is disabling."<sup>194</sup>

Contrasting this perspective with the currently dominant view of the disabled elderly:

[W]hereas "access" and "full participation" have become key concepts for the younger disabled population, for disabled elders, the rights of families and professionals, and of the disabled elders themselves, tend to be far more circumscribed. In this way, aging professionals, elders, and society in general appear to have traded earlier, limited views of aging for an even more limited view of what it means to be old and disabled.<sup>195</sup>

What kind of ethical framework would begin to do the kind of work for the impaired elderly that the developmental model and normalization principle have done for the developmentally disabled for almost thirty years?<sup>196</sup> The following framework is offered as an initial outline for an ethic of long-term care that may have the potential to serve as a guide in the development of a LTC system that is more responsive to consumer preferences and that can help us use what we know about what works to change the way we provide LTC.<sup>197</sup>

The conventional concept of personal autonomy that is

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193. *Id.*

194. GARY L. ALBRECHT, *THE DISABILITY BUSINESS* 35 (Sage Publ'ns 1992).

195. *CRITICAL GERONTOLOGY: PERSPECTIVES FROM POLITICAL AND MORAL ECONOMY* 101 (Meredith Minkler & Carroll L. Estes eds., Baywood Publ'g Co., Inc. 1999).

196. Cohen, *supra* note 186, at 27.

197. GEORGE J. AGICH, *AUTONOMY AND LONG-TERM CARE* 12 (Oxford Univ. Press 1993).

integral to acute care oriented bio-ethics, with its heavy emphasis on an individual's independence, nonintervention, and rational decision-making, does not provide a practical framework for an ethic of long-term care; it is too abstract and removed from the complex realities of LTC.<sup>198</sup> Autonomy is more than just the power of an individual to keep others from intervening in his or her life without fully informed and uncoerced consent.<sup>199</sup> Autonomy is also the power of an individual to interact and communicate freely with others, to give and receive affection, and to initiate actions that are consistent with his or her sense of self.<sup>200</sup> This version of autonomy is especially important in developing an ethic for long-term care.<sup>201</sup> Few persons requiring LTC services fit the bio-medical ethics model of the fully competent, independent individual whose goal is achieving freedom from intervention by others.<sup>202</sup>

We need a richer, more complex concept of autonomy that brings in the real world of the day-to-day life of LTC recipients and recognizes webs of interdependence.<sup>203</sup> This notion of autonomy can shape policies and service strategies that help preserve a disabled person's sense of self and extend the boundaries of his or her own volitional capacities by offering a wide range of home and community-based services, including consumer-directed care.<sup>204</sup>

The development of these programs should not be governed by cost-effectiveness criteria only.<sup>205</sup> There is value in preserving autonomy that should be included in any assessment of LTC costs and outcomes.<sup>206</sup> Just such a perspective guided the

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198. *Id.* at 3.

199. Polivka & Salmon, *supra* note 161, at 17.

200. *Id.*

201. *Id.*

202. AGICH, *supra* note 197, at 10.

203. *Id.* at 12.

204. Polivka & Salmon, *supra* note 161, at 19.

205. *Id.* at 16.

206. *Id.*

development of the first HCBS programs for publicly supported consumers in most states.<sup>207</sup> This vision featured a commitment to quality-of-life values, including autonomy, privacy and dignity, and other values that are more achievable in a person's own home or, if desired, a homelike residential care setting designed to support resident autonomy and control.<sup>208</sup>

An ethics-based critique of current LTC policies for the frail elderly could become as important a force as cost-effectiveness analyses in changing the direction of policy.<sup>209</sup> What is best for the frail elderly, according to their own values and preferences, will become a principle criterion for assessing and developing policy in the direction of LTC policy for the frail elderly, with change occurring in the same way it has occurred for the DD population over the last twenty years.<sup>210</sup>

## BEYOND MEDICAID

Full-scale maximization of currently-available Medicaid HCBS waiver-funding opportunities that has occurred in Oregon and Washington will not be sufficient to meet the level of need for LTC services that will be generated by the aging of the baby boomers.<sup>211</sup> This strategy can certainly create a far more balanced and cost-effective LTC system than most states now provide for the Medicaid-eligible population needing LTC assistance.<sup>212</sup> However, this approach will not provide the level of assistance needed by the large and rapidly growing population of non-Medicaid eligible low-to-moderate-income elderly with functional impairments.<sup>213</sup>

The population of low-to-moderate-income elderly with

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207. *Id.*

208. *Id.* at 20.

209. Polivka & Salmon, *supra* note 161, at 27-28.

210. Cohen, *supra* note 186, at 30.

211. KASSNER ET AL., *supra* note 168, at Washington and Oregon State Profiles.

212. *Id.* at Executive summary pg.

213. HOWARD GLECKMAN, CTR. FOR RETIREMENT RESEARCH AT BOSTON COLLEGE, HOW CAN WE IMPROVE LONG-TERM CARE FINANCING?, No. 8-8 1-2 (2008), available at [http://www.hcbs.org/files/142/7061/long\\_term\\_care\\_finance.pdf](http://www.hcbs.org/files/142/7061/long_term_care_finance.pdf).

LTC needs and without the financial capacity to pay for care on their own will grow by several million over the next three decades.<sup>214</sup> These people must impoverish themselves (spend down) before becoming eligible for Medicaid-supported LTC services, and Medicare provides only a limited home health care benefit and up to 100 days of nursing home coverage.<sup>215</sup> Otherwise, this population is wholly dependent on informal care, out-of-pocket resources, or private LTC insurance, if they are among the 9% of those sixty-five plus who have purchased it.<sup>216</sup>

LTC insurance can be made more attractive (affordable) through more beneficial tax treatment (credits) and other kinds of public policy support, but, as noted earlier, its potential to address the LTC cost challenge effectively is very limited.<sup>217</sup> Although about three-quarters of the population age thirty-five to fifty-nine could theoretically afford LTC insurance, only half now have adequate savings (including home equity).<sup>218</sup> One-third have adequate savings and life insurance and only 20% have, in addition, sufficient health disability insurance.<sup>219</sup> All of these risk management provisions arguably have greater priority than LTC insurance for most families. Only about 20% of persons age sixty and over (the population most likely to consider purchasing LTC insurance) can afford LTC insurance and only 15% of persons age seventy-four and over can afford LTC insurance.<sup>220</sup> Half of the sixty-five plus population is already spending, on average, over 22% of their income in health care costs. This percent is projected to increase to over 30%

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214. LARRY POLIVKA, THE AGING NETWORK AND THE FUTURE OF LONG-TERM CARE: TOWARD A MORE INTEGRATED, CONSUMER-ORIENTED SYSTEM OF CARE 1 (July 2004), available at <http://www.nga.org/Files/pdf/0408Polivka4.pdf>.

215. GLECKMAN, *supra* note 213, at 1.

216. *Id.* at 2.

217. *Id.* at 2-3.

218. MARK MERLIS, KAISER FAMILY FOUND., PRIVATE LONG-TERM CARE INSURANCE: WHO SHOULD BUY IT AND WHAT SHOULD THEY BUY? iv (2003), available at <http://www.kff.org/insurance/6072-index.cfm>.

219. *Id.* at iv.

220. *Id.* at viii.

between 2025 and 2030.<sup>221</sup> Because of the limited funds of elderly, the cost of LTC insurance, and the priority of other risk management provisions, LTC insurance is not a reality for most elderly. Furthermore, the projected increase in the National Retirement Risk Index (NRRI) described earlier may make LTC insurance increasingly less affordable in the future.<sup>222</sup> Baby boomers need to do far more to build their savings than they need to purchase LTC insurance—this task (increased savings) has been greatly complicated by the stagnant/declining wages of the last thirty years and the loss of equity in their homes caused by the housing bubble.<sup>223</sup>

But, even if greater savings and the purchase of health insurance are more important, LTC needs and costs are major challenges for many people and the federal and state governments—challenges that will grow steadily for the next several years, putting great stress on the fiscal capacities of both individuals, families, and government.<sup>224</sup> In the future, the Medicaid program can be expected to provide continuing assistance to about 10 to 20% of the population with LTC needs who meet the program's stringent eligibility criteria. LTC insurance may cover a substantial portion of the LTC needs of another 20% of the population requiring assistance who can afford the premiums. This will leave at least 50 to 60% of the population with LTC needs that will have to be met through out-of-pocket spending and dependence on the shrinking availability of informal care.<sup>225</sup> This is a recipe for the growth of unmet LTC needs and financial distress.

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221. RICHARD W. JOHNSON & RUDOLPH G. PENNER, CTR. FOR RETIREMENT AT BOSTON COLLEGE, WILL HEALTH CARE COSTS ERODE RETIREMENT SECURITY? No. 23 4 (2004).

222. Alicia H. Munnell, *Health-Care Costs Drive up the National Retirement Risk Index*, INVESTMENTNEWS (Mar. 24, 2008), available at <http://www.investmentnews.com/apps/pbcs.dll/frontpage> (type "Alicia H. Munnell" in search box, choose hyperlink at 4).

223. See JARED BERNSTEIN, CRUNCH: WHY DO I FEEL SO SQUEEZED? 20-24 (Berrett-Koehler Publishers, Inc. 2008).

224. MERLIS, *supra* note 218, at 35.

225. Author's calculations based on current and projected realities in LTC.

Several European countries are confronting these realities years ahead of the U.S. because their populations are aging more rapidly. Several of them have begun implementing social insurance systems to fund the provision of universal LTC services with a focus on HCBS programs.<sup>226</sup>

This trend is likely to continue across Europe for two major reasons. First, universal LTC coverage reflects the value that most of these nations have placed on the concept of solidarity among their citizens (a sense of mutual responsibility) social cohesion, and intergenerational reciprocity. Second, universal coverage programs appear to be fiscally sustainable over the next 30 to 40 years with some, mainly Scandinavian countries, experiencing small increases in the already high percentages of GDP spent on LTC (2.5 to 3%), and others with relatively modest projected increases of 1 to 2% . . . .<sup>227</sup>

Recent efforts to reduce future Medicaid expenditures and the conservative campaign to increase the role of private insurance in paying for LTC indicate that the U.S. is not likely to join the emerging trend toward universal public LTC any time soon. The United States' outlier status in terms of LTC and health care policy more generally could change with the aging of the population and shift in the political tide; but for the near future, it would appear that the LTC policy gap between the U.S. and the rest of the post-industrial developed world is likely to widen.<sup>228</sup>

. . . .

Conservative efforts to privatize the Medicare program, or to prevent expanding eligibility for LTC services in the Medicaid program, are part of a larger ideological initiative. This initiative is designed to diminish the public sector and privatize as many traditional government functions as possible at the

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226. LARRY POLIVKA, *THE GLOBAL FLORIDA AND LONG-TERM CARE ACROSS POST-INDUSTRIAL COUNTRIES 13* (forthcoming) (citing MARY JO GIBSON ET AL., AARP PUB. POL'Y INST., *LONG-TERM CARE IN DEVELOPED NATIONS: A BRIEF OVERVIEW 2003-23* vi (2003), available at [http://assets.aarp.org/rgcenter/health/2003\\_13\\_ltc\\_dv.pdf](http://assets.aarp.org/rgcenter/health/2003_13_ltc_dv.pdf)).

227. *Id.*

228. *Id.* at 13-14.



federal, state, and local levels by contracting out these functions to . . . corporations . . . .<sup>229</sup>

The rationale for sweeping privatization is based on conservative economic theory, which is now often referred to as neoliberalism and the notion that market competition is the most efficient method of allocating goods, including those like health, education, and social services that are often thought of as "public" goods.<sup>230</sup> Contracts, however, are often awarded in the absence of any true competition and little follow-up accountability. There is very little evidence supporting the superior efficiency and cost-effectiveness of privatization compared to government-operated programs. For example, the Medicare Managed Care program, which is dominated by proprietary HMOs, has never demonstrated greater efficiency or better clinical outcomes than the traditional Medicare program.<sup>231</sup>

The Medicare Advantage program, which is the private managed care part of Medicare serving about 20% of all beneficiaries, *actually costs 13% more* than the traditional program.<sup>232</sup>

The privatization of the Medicaid program through contracts with managed care organizations, which are mainly proprietary HMOs, is also proving to be more expensive than the traditional fee-for-service Medicaid program.<sup>233</sup> This trend is raising serious questions about the cost-effectiveness of proprietary managed care organizations in the Medicaid program, which is the principal funding source of publicly supported LTC services in every state. Policy makers have long assumed that Medicaid HMOs, which now serve 63% of all

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229. *Id.* at 15.

230. *Id.* at 15 (citing David Harvey, *Neoliberalism as Creative Destruction*, ANNALS AM. ACAD. POL. & SOC. SCI., available at <http://ann.sagepub.com>).

231. *Id.* (citing JOHN GEYMAN, *SHREDDING THE SOCIAL CONTRACT: THE PRIVATIZATION OF MEDICARE* 85 (Common Courage Press 2006)).

232. See MEDICARE PAYMENT ADVISORY COMM'N, A DATA BOOK: HEALTHCARE SPENDING AND THE MEDICARE PROGRAM 153 (2008), available at [http://www.medpac.gov/documents/Jun08DataBook\\_Entire\\_report.pdf](http://www.medpac.gov/documents/Jun08DataBook_Entire_report.pdf).

233. Bruce Spitz, *Medicaid Agencies as Managed Care Operations: An "Actuarially Sound" Solution?* 32 J. HEALTH POL., POL'Y & L. 379, 379 (2007).

Medicaid clients, always improve quality, expand access, and decrease costs, even when national studies indicate that they do not. Policy makers could maintain this pretense because the rate setting methodology guaranteed that capitated systems would always cost less than fee-for-service programs.<sup>234</sup> This all changed in 2003 when:

The federal government required states to set capitation rates that were “actuarially sound.” Actuaries were formally brought into the process, and the American Academy of Actuaries developed guidelines. If states were passive entities, actuarially sound rates would have health maintenance organizations (HMOs) become for Medicaid what they have already become for Medicare: the high-priced alternative to fee for service (Berenson 2004) (p. 379).<sup>235</sup>

Several instances have been documented over the past four years when the calculation of “actuarially sound” rates for Medicaid HMOs have generated Medicaid costs 10 to 20% greater than would occur under fee-for-service programs.<sup>236</sup> This greater cost is largely a result of having to meet the “actuarial soundness” provisions related to administrative costs, which are substantially greater than in the fee-for-service system and “appropriate” profit margins.<sup>237</sup>

[S]tates will respond to the higher actuarially sound rates when they understand that they have lower-cost options. We also know that as Medicaid enrollment continues to climb, states will be forced to manage their Medicaid programs even more aggressively. A reasonable expectation would be that many states will develop or contract for the management functions that will permit the state Medicaid agencies to become public managed care organizations while reimbursing their providers on a fee-for-service basis. In other words, the states will become the managed care organizations they had always hoped they could bring

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234. *Id.*

235. *Id.*

236. *Id.*

237. Spitz, *supra* note 233, at 406.

into their programs.<sup>238</sup>

In the case of LTC, many states already have much of the infrastructure in place that would be needed to develop a managed care alternative to expensive proprietary HMOs—the non-profit aging network organizations that have been providing publicly funded community-based services for over twenty-five years.<sup>239</sup>

## CONCLUSION

The need for LTC services will grow at an unprecedented rate over the next thirty years with the aging of the baby boom generation, and the current gap between what we know and what we do in LTC will become increasingly difficult to ignore.<sup>240</sup> The progress a few states have made in creating balanced LTC systems by offering an increasingly extensive array of cost-effective home- and community-based services offers compelling evidence for the feasibility of policy initiatives to close the knowledge and practice gap in every state. The initiatives could be expedited by new federal (Congress & CMS) incentives designed to increase the utilization of Medicaid home and community-based waivers by the states.<sup>241</sup> These might include a greater Federal Medical Assistance Percentage (FMAP) contribution, or waiver-funded programs, possibly 20 to 25% more than for the regular state plan Medicaid programs like nursing home care. Comprehensive LTC reform, however, on a scale responsive to the projected increase in the need for care and the associated costs, will require more than improvements in Medicaid-funded programs for impoverished disabled persons and private LTC insurance for the more affluent.<sup>242</sup>

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238. *Id.* at 408.

239. MARY JO GIBSON ET AL., AARP PUB. POL'Y INST., LONG-TERM CARE IN DEVELOPED NATIONS: A BRIEF OVERVIEW 2003-23 vi (2003), available at [http://assets.aarp.org/rgcenter/health/2003\\_13\\_ltc\\_dv.pdf](http://assets.aarp.org/rgcenter/health/2003_13_ltc_dv.pdf).

240. Rosenbaum, *supra* note 175, at 29.

241. BURKE, *supra* note 148, at 13.

242. *Id.* at 11-12.

Advocates, policy makers, and the media should begin now to initiate a national conversation focusing on whether LTC financing in the future should rest on a private or public foundation or a new public-private partnership. Public policy changes can improve and extend private insurance, but its benefits are likely to be limited to the top 20 to 35% of the income distribution; it has little potential to spread the risk of high LTC costs for the rest.<sup>243</sup> Even if public policy change is accompanied by a universal, publicly-funded, catastrophic benefit, a strategy grounded in private insurance will enhance protection primarily for older people with higher incomes, leaving most people with disabilities, of which a relatively small percentage meet eligibility criteria, at considerable risk of not receiving the care they need.<sup>244</sup> Making private LTC insurance policies better for those who can afford them makes sense, but making it the centerpiece of the nation's LTC policy does not.<sup>245</sup>

Incorporating LTC needs and costs into the debate over the future of U.S. health care will help raise the consciousness of the American people and their policy makers regarding relationships between foreign policy goals and military spending; fiscal policy (tax cuts and deficits), the future sustainability of the major entitlement programs (Social Security, Medicare, and Medicaid), emerging domestic challenges like LTC needs and costs, and the capacity of impaired persons to cover these costs on their own. The fundamental public policy question is: "Will the electorate support a political agenda designed to reduce current public programs like Medicare, and preclude new programs like universal LTC social insurance, through 'starve the beast' strategies based on increasing military budgets, tax cuts, diminished revenues, and growing deficits?" This is a fundamental political, ethical, and quality-of-life issue that profoundly affects all but the most affluent.

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243. *Id.*

244. *Id.*

245. *Id.* at 3-4.

